



Psychosocial Issues that Affect Youth with Diabetes

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ABSTRACT

Type 1 diabetes, one of the most common diseases of childhood, requires adherence to a complicated regimen which is often times difficult to manage resulting in stress for children, siblings, and caregivers. Many children with diabetes are nonadherent, likely due to the difficulty and complexity of the tasks required, and, thus, are at greater risk for diabetes related complications. For health care educators, it is important to understand the various psychosocial issues that affect adherence and adjustment to diabetes. This article will discuss these issues, including coping with a new diagnosis, school factors, regimen adherence and family variable and parenting strategies. Recommendations for health care educators are also discussed.

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INTRODUCTION

Type 1 diabetes (T1D) is a difficult and taxing disease for children and adolescents. It requires the family to balance challenging medical tasks (e.g., blood glucose monitoring, multiple daily insulin injections, dose calculations, advanced level of problem solving or decision making) with dietary modification and exercise into already complex daily lives to maintain stable blood glucose levels to prevent complications to growth and development. Considering the level of difficulty, it is not surprising that 50% to 55% of youth are nonadherent and as many as 30% to 50% of youth with T1D are in poor glycemic control.¹ As a result, these children face severe health complications such as increased risk for diabetic ketoacidosis

(DKA), damage to major organ systems and premature death.¹⁻³ In addition to the direct

consequences, nonadherence may impact clinical decisions made by health care pro-

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viders, such as increasing insulin doses for high blood glucose levels when, in fact, high glucose concentrations are due to failure to follow the diabetes regimen. Further, poor adherence results in medication abuse and excessive use of health care services.^{4,5}

Understanding factors associated with adjustment and adherence is important for anyone working with children and adolescents with diabetes, as better adherence may translate to improved glycemic control.⁶ Adherence to the diabetes regimen is influenced by many factors, such as initial adjustment and acceptance of the illness as well as coping with behavioral, school and family stressors. Given the severity of complications resulting from poor glycemic control, health educators must be knowledgeable about these various psychosocial factors in order to help identify youth at risk for poor adjustment to their diabetes and to guide strategies aimed at improving regimen adherence.

COPING WITH A NEW DIAGNOSIS

Diabetes is one of the most common chronic illnesses of childhood with more than 13,000 new diagnoses occurring each year.⁷ A diagnosis of type 1 diabetes elicits a number of emotions and grief reactions including anger, sadness, guilt and anxiety which typically resolve within the first year.⁸ Psychosocial acceptance and adaptation to the illness can impact long term adjustment for both children with diabetes and their families.

When a child is diagnosed with diabetes, parents must learn a large amount of new information and many new skills to care for their child adequately, while experiencing a wide range of emotions, including shock, grief and guilt. Parents often attempt to cope with the diagnosis using a variety of strategies that may be helpful or may interfere with the child's ability to cope.⁹ Some parents have difficulty accepting the information and cope by denying that their lives will change or that diabetes will affect them.¹⁰ Other parents respond with anxiety and attempt to control more aspects of the child's life. After time, parents may find a healthy balance between being involved in

their child's care and allowing freedom to be a child. It is important to help parents to establish realistic expectations about management of diabetes, financial costs, reasonable glycemic control and methods for treating hypoglycemia.

Children experience a number of emotions after learning they have diabetes, including anxiety, depression, and social withdrawal.^{9,10} Most children return to baseline within seven to nine months, however a number of children experience long-term adjustment difficulties.^{11, 12} Poorer health is associated with poorer adjustment.¹³ Children entering middle childhood and adolescents face difficult social challenges in terms of developing their independence and unique identities, and developing peer relationships.⁹ Diabetes may complicate many of these issues due to fear of stigmatization from peers, teasing from peers and heightened awareness of differences and sense of inadequacy. These events may impact self-esteem which is associated with poorer control.¹⁴

DIABETES AND THE SCHOOL SETTING

Children with chronic diseases tend to be absent from school more often.¹⁵ Reasons can include poor health, physician appointments and school refusal. Children with diabetes who are in poor control are particularly at risk as they experience more hospitalizations and physical complaints. Further, parents may experience anxiety about sending their children to school for fear that staff members are not as capable of caring for a child with diabetes. Children are more likely to have feelings of separation anxiety due to heavy reliance on parental care. Children who fear stigmatization or teasing may develop school phobias and avoidance. Also, children may learn to use high and low blood sugar episodes as means of avoiding aversive or unpleasant tasks, such as taking tests or attending particular classes.

Children with diabetes typically demonstrate average cognitive abilities but may experience some mild learning or neuropsychological deficits subsequent to

their illness. Some mild deficits in verbal intelligence, attention, memory and executive functioning have been noted, especially in children diagnosed under the age of four who have experienced many hypoglycemic episodes.¹⁶ These factors are particularly relevant as they impact the ability of children to successfully manage their own health care. Adolescents with decreased executive functioning will not be able to plan and organize their own health behaviors adequately, and will, therefore, have poorer adherence once responsibility for diabetes care shifts from the parent to child.¹⁴

It is important to establish and maintain frequent contact with school staff members to maximize school success. Information should be shared about out of range blood sugars, regimen details and treatment responses. Staff members should be knowledgeable about the need for snacks during physical activities, the need to check blood sugars at appropriate times and the need for administration of insulin and meals at scheduled intervals. Children should be encouraged to participate fully in all activities to minimize the perception of differences between the child and his or her peers.¹⁷

ADHERENCE TO THE REGIMEN

Adherence and control describe two different aspects of diabetes management. Whereas adherence refers to the degree to which the child is completing health-related behaviors as prescribed by the physician, control refers to the metabolic status reflecting the degree to which blood glucose levels are in the normal range.¹⁴ Children may be relatively compliant and still exhibit poor control. Furthermore, children will typically demonstrate adherence to one or more aspects of their diabetes care while being noncompliant with others. Parents should be encouraged to participate in their child's diabetes management to the degree necessary for the child to succeed with disease management. Health care professionals may be helpful in establishing concrete strategies for children and their parents to use to establish better control.¹⁷ For example, by setting small, specific, manageable and



realistic goals that they can work toward, the family will experience greater feelings of efficacy over their management of the illness. Assessing the family's motivation for change can provide valuable information about how to approach goal setting in children experiencing management difficulties.^{18, 19} Some families may feel overwhelmed and, therefore, avoid change. These families will require considerable support before moving into a more action focused phase.¹⁸ Several assessment strategies are helpful such as self-report and observational health measures, physician ratings, behavioral observation of health behaviors and 24-hour recall interviews.¹⁴ It is also important to assess the diabetes-related knowledge levels and general problem solving skills to identify any deficits that may lead to inadvertent non-adherence.¹⁴

Children may display maladaptive behaviors that adversely affect adherence.¹⁴ When children have poorly controlled blood sugar levels it is helpful to assess if they are skipping insulin injections or administering excess insulin. Because insulin is necessary for weight gain and development, the side effect of too little insulin includes weight loss in addition to hyperglycemia. Failure to administer insulin injections, resulting in recurrent hospitalizations for DKA may be a cry for help or a marker of depression or suicidal ideation. Finally, there is an increased prevalence of eating disorders in children with diabetes, as habitual dietary restraint can lead to binge eating, and these children must, therefore, be monitored for bulimia and other eating disorders.²⁰ Moreover, fear of hypoglycemia and fear of embarrassment if seizure occurs or a child or adolescent passes out in front of peers is a major barrier to good glycemic control. Parents may also unnecessarily and excessively restrict the intake of carbohydrates to prevent high blood sugars.

FAMILY VARIABLES

The family environment appears to be particularly important in the adjustment of children with a chronic illness such as diabetes.²¹ Whereas research indicates that high

family cohesion is positively correlated with good glycemic control,²² low family cohesion is associated with high levels of avoidant coping.²³ Research also indicates that there is a bi-directional relationship between family stress and glycemic control. That is, high levels of family stress are correlated with poor control and poor control can produce family stress.²⁴ Children with poor glycemic control were more likely to use maladaptive coping strategies than those with good glycemic control.²⁵ In addition, high levels of family conflict, especially during adolescence are associated with poor metabolic control.²⁶ Conversely, positive family communication and problem solving skills are correlated with good adjustment.²⁶ Furthermore, when children perceive their parents as warm and supportive, they are less likely to experience episodes of DKA²⁷ whereas youth who report critical parenting related to their diabetes management were more likely to be in poor glycemic control.²⁸

PARENTING AND ADHERENCE

Some parents attempt to control all aspects of their child's care and even provide rigid rules and structure in other areas of their lives with resultant parent-child conflict.¹⁴ For example, parents may not allow children to attend social functions or visit friends to monitor health behaviors more closely. Other parents prematurely place full responsibility on the child, despite the child having inadequate cognitive, emotional and behavioral maturity. An example of this phenomenon involves parents who feel the child should remember to check blood glucose levels, count carbohydrates, calculate and then administer the appropriate amount of insulin with meals. This complexity may lead to frustration and a sense of failure for both the child and the parent if the child is not yet ready to accept that level of responsibility. Both strategies often result in nonadherence and poor metabolic control.

In terms of overly controlled parents, it is helpful to problem-solve about ways to increase responsibility and manage their own anxiety. Health professionals can emphasize that youth are more likely to be

adherent if they feel they are participating in the decision making process regarding their own diabetes. Children and adolescents should be given as much responsibility as they can handle successfully within their developmental level. Conversely, for parents who have abrogated their responsibility too early, it is necessary to convey that diabetes is a family disease and that increased parental monitoring and supervision is essential.²⁹ Supervision of the diabetes treatment regimen needs to be carried out in a developmentally appropriate way. For instance, parents of younger children are likely to have primary responsibility for administering treatments. As children mature, primary responsibility for the diabetes-related tasks may be reduced as the child demonstrates being able to accept more self-care responsibility. However, supervision before and during adolescence continues to be of critical importance. The parent must understand that children have poorer diabetes outcomes when their self-care responsibilities exceed their psychological maturity.³⁰

PARENTING STRATEGIES

Parents can learn more effective techniques for supervising and helping to manage health behaviors. Behavioral strategies, such as contracts, monitoring behaviors (e.g., reviewing the pump history every night), successive scaffolding of responsibility, praising and encouraging, and employing token economies (e.g., tokens or points, which are earned by completing desired behaviors, can be exchanged for greater rewards such as a trip to the movies) are most effective in promoting adherence.^{31, 32} Parents are recommended to balance their involvement in their child's care with the child's desire for independence and need for gradual increased responsibility in a supportive and encouraging manner while avoiding negativity, criticisms, nagging and verbal or physical aggression.

Positive parenting strategies such as conveying warmth, encouragement and praise are often associated with better adherence.³³ The use of encouragement increases self-esteem, and builds feelings of self-efficacy.



It is recommended that parents focus on the positive, on what the child did correctly, such as monitoring blood glucose checks or remembering insulin administration, rather than pointing out times he or she had to be reminded. Parents are encouraged to reward rather than punish and to focus on assets and strengths to help children learn from mistakes. Supervision and monitoring should occur in a sympathetic and constructive way while also emphasizing the importance of adherence.³⁴

Behavioral strategies can be helpful for increasing the cooperation with regimen behaviors.³⁴ A behavioral contract is often a successful tool for getting the youth to “buy in” to their diabetes treatment regimen.³¹ A behavior contract is an agreement that is written by both the child care diabetes team and the child, which gives the child explicit behavioral goals and allows the child to earn small weekly rewards or privileges by fulfilling verified treatment and testing requirements. Effective contracts are based upon genuine negotiation among adolescents and parents, or members of the diabetes team and families and encompass clearly defined goals, and methods of verifying progress toward those goals. Behavioral incentives are another effective tool that can bridge the gap between the long term benefits of adherence and the immediate benefits from adherence that ultimately are more meaningful to children and adolescents.

RECOMMENDATIONS

Health care educators can help parents and school staff by directing them toward education materials about diabetes such as basic guides or other web based resources. Also, it is normal for parents and children to experience many emotions and normalizing feelings such as sadness, anger, guilt, or anxiety can help them understand, cope with and respond more effectively to their grief. Individuals working with these patients can respond best by using active listening skills and being empathic (“It sounds like you feel really scared.” “You are not sure what is going to happen.” “Diabetes is scary.”). Patients should be encouraged to express their

feelings and concerns without judgment or attempts to decrease their emotions (“Tell me more. I want to know how you feel.”). Patients that are experiencing emotional concerns in excess of what is expected from the natural expression of grief and coping with a chronic illness should be referred to a professional mental health counselor.

Children and families coping with diabetes face a number of challenges in addition to complex medical regimens. Adjustment and quality of life in children with diabetes is affected by many factors, the most important being family support and ability of the family to cope with the emotional reactions to a chronic illness such as depression, anger, anxiety and guilt. Further, living with a chronic illness can impact the social lives of youth in the school as well as at home and may affect their ability to have healthy interpersonal relationships. Parent response and coping is one of the best predictors of successful adjustment and behavioral strategies and positive parenting can help youth better respond to the stressors in their lives. Health care professionals can help parents and children by being knowledgeable about these issues in order to provide assessment, support and education as needed. Further, being aware of potential psychosocial issues can help those working with children and adolescents with diabetes decide when to make referrals to mental health professionals.

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